Involving older people in gerontological nursing research

TITLE

Involving older people in gerontological nursing research: a discussion of five European perspectives

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CITATION

Blakey, E., Durante, A., Malfait, S., Panayiota, K., Thilo, F., & O'Connor, S. (2020). Involving older adults in gerontological nursing research: a discussion of European perspectives. *International Journal of Older People Nursing,* 15(2):e12311. https://doi.org/10.1111/opn.12311

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KEYWORDS

Older adult, gerontology, nursing research, involvement, participate, co-design, co-produce

ABSTRACT

This paper describes involving patients and the public in nursing research and discusses the challenges and opportunities in adopting this approach during a doctoral training programme. The paper summarises patient engagement initiatives across a number of European countries, draws on some key literature and critically reflects on the perspectives of doctoral students undertaking gerontological nursing research in Europe. It concludes with a number of recommendations on how to include older people as active partners in doctoral nursing research.

ACKNOWLEDGEMENTS

We would like to thank a number of colleagues who contributed to initial discussions on involving older people in gerontological nursing research, in particular during doctoral training programmes. These were Nienke Dijkstra and Linda Smit (University of Applied Sciences Utrecht, The Netherlands), Irene Gspoerer (Medical University of Graz, Austria), Deborah Rosa (L'Università degli Studi di Milano, Italy) and Ashleigh Ward (University of Stirling, United Kingdom). Their thoughts and perspectives stimulated this discussion paper which we gratefully acknowledge here.

CONFLICT OF INTEREST

Emma Blakey is a Social Media Editor for the International Journal of Older People Nursing. Dr Siobhan O'Connor is an Associate Editor for the International Journal of Older People Nursing.

FUNDING

None

BACKGROUND

This exploration and discussion about involving patients and the public in gerontological nursing research, in particular doctoral training programmes, was prompted by conversations at a European summer school for doctoral nursing students. As nurses from different regions of Europe, we felt our experiences of postgraduate study and nursing scholarship had much in common. However, it also varied in some respects particularly around the approach to including patients, informal carers (family or other untrained and unpaid care providers) and the public in the research process (de Wit, Cooper, & Reginster, 2019).

This raised a number of questions about how and when to incorporate this approach into doctoral training programmes across Europe with its diverse culture, healthcare and higher education systems. Our response was to come together as a group of early career researchers to review national initiatives around involving patients and the public in health research. We then identified some key literature that used this approach within gerontological nursing and critically reflected on our own experiences during our doctoral studies, which involved or had the potential to involve older people. This work is discussed and a number of recommendations put forward that could improve nursing science and patient care.

Gerontological nursing research

Nursing has traditionally focused on caring for and supporting older people and their families, as this population tend to have more complex health and care needs. Hence, gerontological nursing research has a long history of examining and addressing, where possible, issues faced by older people. This lies at the heart of improving population health and wellbeing as we all experience and are affected by aging. Since the publication of the first geriatric nursing standards in 1968 (Pierre & Conley, 2017), the evidence base on how nurses can best care for and support older people has been evolving. Evidence based practice

(EBP) combines clinical expertise, with scientific evidence and patient values to help ensure decisions made by professionals include all-important perspectives so that the best outcomes can be achieved (Mockford, Staniszewska, Griffiths, & Herron-Marx, 2012). While this 'episteme' emphasises partnership with patients when making decisions and delivering care, some argue this relationship needs to be considered through a Foucauldian lens in order to guard the delicate balance between knowledge and power (Holmes & Gagnon, 2018). This partnership needs to be carefully managed as it could become exclusionary and lead to nurses and other professionals controlling the health and wellbeing of older adults by imposing unnecessary or unwanted interventions.

Aside from this, other shortcomings in EBP have also become more apparent. The limited time and resources available to conduct high quality research, along with statistically significant results that have little or no clinical impact are further issues. Evidence focusing on single diseases which are difficult to apply to individual patients with complex health issues is also problematic (O'Connor, Deaton, Nolan, & Johnston, 2018). In addition, numerous barriers such as funding and clinical leadership can affect the adoption of evidence into practice and it can be challenging for older people to integrate research evidence into their daily lives. Importantly, patients' and informal carers' values and preferences are sometimes ignored during the EBP process (DiCenso, Guyatt, & Ciliska). This means significant amounts of time and resources can be spent conducting health research, some of which has little impact on the people who are meant to benefit. The values that underpin nursing research such as autonomy, beneficence, maleficence and justice, among others, require a more nuanced approach to the social systems and structures underpinning EBP, as some of its practices and norms are socially and ethically questionable (Springer & Clinton, 2015). Hence, these difficulties have led to a renewed focus on the active involvement of patients and the public in all aspects of the research process (Brett et al., 2014).

The move to include patients and the public in health research began in oncology and from there spread to other fields including gerontology (Abma, Pittens, Visse, Elberse, & Broerse, 2015; Street, Voigt, Geyer, Manning, & Swanson, 1995). Internationally, this movement has many names. It is referred to as patient engagement in the United States (Smith et al., 2015), it is known as Patient and Public Involvement (PPI) in the United Kingdom (Locock et al., 2019), and consumer and community participation in Australia (McKenzie, Alpers, Heyworth, Phuong, & Hanley, 2016) among others. The reported benefits of this approach encompass three main areas; 1) enhancing service planning and development, 2) improving information development and dissemination, and 3) positively changing the attitudes of healthcare providers and service users towards each other (Mockford et al., 2012). It is anticipated that the continued involvement of patients and members of the public in health research, will lead to significant long-term improvements in how health services function and the outcomes of those who use them.

Patient and public involvement in research: European perspectives

While Europe is made up of fifty sovereign states, we focused on the five countries where we undertook our doctoral studies to represent a snapshot of contemporary practice in relation to patient and public involvement in nursing research.

In the United Kingdom, the INVOLVE network (https://www.invo.org.uk/) was established by the National Institute for Health Research in 1996. It supports the active involvement of patients and the public in government funded health and social care research. It aims to include them in identifying, prioritising, designing, undertaking and disseminating research to ensure it is more effective, credible and optimised in terms of cost-benefit. The INVOLVE network has clearly stated what it means by members of the public and patients participating in research. It must be planned and active in terms of 1) consulting, 2)

collaborating, and 3) undertaking user-controlled research. Examples of consultation may include asking the public to help identify research priorities or reviewing and providing feedback on dissemination plans. In terms of collaboration, it might involve an ongoing partnership so people can become actively involved in writing research grants or providing oversight of an ongoing research project through an advisory group. Finally, in user-controlled research, service users or their associated organisations can assist in planning and conducting research activities such as developing new methodological approaches or facilitating data collection and analysis (Locock et al., 2019).

In Italy some regions, such as the Regional Health System of Emilia-Romagna, have introduced programmes to include patient associations in Mixed Advisory Committees to assess the quality of healthcare (Serapioni & Duxbury, 2014), although this does not extend to research. Italy is also a member of the European Patients' Academy (EUPATI) network. EUPATI is a pan-European project implemented as a public-private partnership by a collaborative multi-stakeholder consortium from the pharmaceutical industry, academia, not-for-profit, and patient organisations (https://www.eupati.eu). They are building a network across the continent to bring patients, academia and industry together when developing new drugs to ensure the needs of patients and their families are included. Other patient organisations, such as the Italian Association for Heart Failure Patients, have been involving patients in research by collaborating with universities. However, there is still no consistent and systematic approach to this in Italy.

In the Flemish speaking part of Belgium, the Flemish Patient Platform (Vlaams patiëntenplatform; http://vlaamspatientenplatform.be) is an independent umbrella-organisation for all patient peer support groups in Flanders, which also professionalises patient representatives. The organisation aims to contribute to the quality of life of patients and their community by being their advocate at all policy levels and within healthcare

organisations. First, they focus on bringing patient association groups together, stimulating cooperation between these groups and organising joint advocacy. Second, the organisation strives to provide solutions for bottlenecks concerning the care around chronic conditions. Third, they train patient representatives and provide the needed know-how to participate in various activities e.g. policy, research, consultancy. Finally, they aim to disseminate relevant information to patient associations and citizens and in this way stimulate citizen participation in public health policy. The Flemish Patient Platform is subsidised by the Flemish Government but functions independently. Unfortunately, in the French speaking part of Belgium there is not yet an equivalent organisation for involving patients and the public in health research.

In Greece, there is no official body to promote patient or public involvement in health and nursing research. (Boudioni, McLaren, & Lister, 2018) suggests this may be due to an underdeveloped third sector with few organisations that champion patient's rights in the country and not enough legislation explicitly requiring this approach in the Greek healthcare system. Some mechanisms exist to give patients more of a voice such as the Independent Patients' Rights Protection Service (IPRPS) (Αυτοτελής Υπηρεσία Προστασίας Δικαιωμάτων Ασθενών) and the Patients Rights' Protection and Control Committee (PRPCC) (Επιτροπή Ελέγχου Προστασίας Δικαιωμάτων Ασθενών) (Graham, Susan Margaret, & Markella, 2012). However, these tend to focus more on involvement in health service delivery and do not specifically address research. This often means that the use of participatory approaches is dependent on individual researchers and their interests. Thus, involving lay people in nursing research may be used in Greece although it is not yet a strategic priority.

In Switzerland, there are national recommendations but no obligations for healthcare providers or scientific institutions to include patients or the public in research. A strategy published by the Swiss Federal Office of Public Health, called Health 2020, highlighted that

this needs to be a priority going forward to improve the health system (Federal Office of Public Health, 2013). The Swiss Academy of Medical Sciences provides guidelines on valuing and encouraging patient and public involvement (Swiss Academy of Medical Science, 2016). This defines the meaning of patient involvement, gives an overview of activities in Europe, details the added values of patient and public participation in research and at different levels of the healthcare system, as well as focuses on possible challenges related to this approach. However, despite a lack of coordination at a national level, individual universities in Switzerland are taking action to involve patients in education, clinical practice and research (Gurtner & Hahn, 2016).

Experiences of including older people in doctoral nursing research

Upon critically reflecting on our experiences as doctoral students, some common themes emerged in relation to involving patients and the public in our research. While our topics spanned a number of areas of gerontology from hospital readmissions and bedside handovers, to gerotechnology, and physical activity in older people, very few included them as active participants in the research process. The most common method was to gather the characteristics and perspectives of individuals over the age of sixty-five and the health professionals who support them through a combination of qualitative and quantitative methods (Durante, Greco, et al., 2019; Malfait et al., 2018). In some cases, informal carers were also recruited to our studies as research participants (Durante, Paturzo, et al., 2019; O'Connor, 2019).

In a few cases, patients were more actively involved in the research. In one study, older people were involved in co-designing and testing a wearable fall detection device (Thilo, Bilger, Halfens, Schols, & Hahn, 2016; Thilo, Hahn, Halfens, & Schols, 2019). In another, older patients with end stage renal disease led the researchers to identify meaningful

research questions through the completion of a quality of life and treatment questionnaire. They also took part in designing the study by evaluating the feasibility of the study protocol. Moreover, older people reviewed the consent and participant information sheet in terms of comprehension from the lay perspective. Another doctoral student also involved older people in reviewing ethical documentation and used creative evaluation methods with older people to inform the analysis process.

Overall, there was a lack of active engagement in older people in our doctoral research which stemmed from our limited awareness and understanding of the importance of this approach. Other barriers included a lack of time, resources, and research experience. Furthermore, this way of working with older people is not yet fully embedded in the research culture of local and national institutions. Some universities do prioritise and provide training in this area but it is implemented on an ad-hoc basis and not universally available. In addition, certain funding agencies and academic journals require patient involvement in research before considering grant applications or scientific articles for peer-review but this practice is not widespread. Hence, our experiences reflect the wider research environment of nursing and healthcare more generally.

Discussion

When patients and the public are being included in gerontological nursing research, this seems to bear fruit. (Reuben et al., 2017) highlighted that a patient and stakeholder council reviewed and improved procedures, algorithms and educational material for a new falls prevention intervention. This made it more acceptable to research participants and feasible to implement in a clinical trial in the United States. (Elliott et al., 2017) also demonstrated that participatory action research involving older persons enhanced medication management in nursing home services in Australia. (Manafo, Petermann, Mason-Lai, & Vandall-Walker,

2018) provide a comprehensive overview of improved outcomes for patients as a result of engaging them in health research in Canada. These included patients gaining confidence and life skills, improved quality of care due to setting research priorities, better trust between, researchers and patients, and improved information on diseases and treatments among others. While a systematic review on this topic already exists in the healthcare domain (Shippee et al., 2015), a comprehensive review focusing on patient involvement in gerontological nursing would be useful to highlight aspects specific to older adult populations.

Within Europe some studies also indicate a positive impact. In the United Kingdom, a study jointly funded by the INVOLVE network explored the impact of patient and public involvement within clinical trials and found it improved the design and conduct of the trial (Dudley et al., 2015). (Blackburn et al., 2016) also described how a user research group co-produced self-reported quality indicators for people with osteoarthritis. This led to enhanced quality care indicators for use in research and primary care practice and the new tool has already been used in a number of European countries. (Geissler, Ryll, Di Priolo, & Uhlenhopp, 2017) discussed the benefits of patient involvement in all stages of medicines research in Europe and emphasised it could lead to better therapies that represent patients' needs while also improving recruitment and retention in research studies and enhancing the dissemination of findings. (Supple et al., 2015) also supported the active inclusion of asthma patients and carers of people with asthma in a European study looking at biomarkers in predicting respiratory diseases. Three large patient organisations received funding to work with a consortium of academic and industry partners, meaning patients were involved in all aspects of this research study. This included writing the funding application, participating on ethics committees and advisory boards, designing recruitment processes, reviewing the progress of the research and sharing results. The authors report this had numerous benefits

from to faster and more comprehensive participant recruitment, a more adaptable data collection methods, and wider advocacy of the project and its findings.

However, our experiences in Europe have illuminated there is a lack of emphasis in doctoral programmes about the importance of involving patients and the public in the research process and how this should be done. This may reduce the impact of nursing science and the quality of health and care long-term. Given large amounts of public money are spent on health research including the people who fund and are affected by its outcomes is critical to ensure improvements in older people's health and wellbeing. Therefore, we propose a number of recommendations to incorporate this approach into doctoral nursing training programmes. These are aimed at policy makers, research institutions, and individual researchers.

Policy makers

- Produce clear guidelines defining patient and public involvement in research, along with outlining the roles and responsibilities of doctoral students, supervisors, researchers, and support staff. These could be combined with the necessary processes and systems to support this type of initiative in a clear framework that outlines how involving older people in health research will work. This should take into account the heterogeneity of older populations and the ways in which people from different ages, genders, ethnicities and socioeconomic backgrounds may wish to participate.
- Invest funding both nationally and locally to support the involvement of older people in health research, as this type of imitative requires significant amounts of time, expertise and resources for it to be realised.

Research institutions

- Implement relevant national and international guidelines on patient and public involvement in health research.
- Establish a dedicated older patient forum within or across research institutions to provide support for older people who wish to become actively involved in health research.
- Offer research methods training for older patients, informal carers, and the public so they can take part in a research study to a level that would benefit it and them. This may include training on ethics, research designs, reviewing literature, data collection, analysis or dissemination. A database could also be set up to enable nursing researchers to contact interested members of the older people forum to facilitate their involvement in research. Compensatory mechanisms for the time and expertise older people contribute to a study may also need to be considered.
- Provide opportunities to patients, informal carers, and the public to take part in creating educational resources and delivering training programmes that teach nursing students, at bachelor, masters and doctoral level, and faculty about patient and public involvement in research.
- Include an older health service user perspective in ethics committees and give constructive feedback to applicants on ways to include patients or the public in a research study, where appropriate.
- Set up and maintain partnerships with health service providers, voluntary or third sector agencies and other professional groups who support older people as they may need to be included in a research study to help ensure positive outcomes are reached.

Individual researchers

- Seek out opportunities to learn how to involve older people in health research as equal, active partners and consider study designs that can incorporate this approach, where appropriate.
- Include older people in some aspect of the research, where possible, and promote this through informal and formal networks, in particular within the doctoral student community.
- Highlight barriers for involving older people in health research so that these may be addressed in the future.

This list of recommendations is not exhaustive and we invite further commentary from all stakeholders, in particular older people, on other initiatives that could help make involving patients and the public in gerontological nursing research a reality.

Conclusion

This brief discussion on involving older people in gerontological nursing research is not intended to be an exhaustive overview of the field, but highlights key issues and areas for further development which are needed to improve nursing science going forward. We hope it stimulates further discussion within the gerontological nursing community about the benefits, risks, and limitations of actively including older people in our research and that this leads to improvements in doctoral training programmes worldwide. As people are living longer lives, we believe it is important to take the next steps towards a more inclusive nursing research culture. One that values the perspectives of older people throughout their lifespan and enables us to work together to shape our shared future.

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